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# The Experience of Latino Parents of Hospitalized Children during Family Centered Rounds

Lisa Ann Walker-Vischer

*Northern California Consortium, Doctor of Nursing Practice Program, California State University, Fresno and San José State University*

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THE EXPERIENCE OF LATINO PARENTS OF  
HOSPITALIZED CHILDREN DURING  
FAMILY CENTERED ROUNDS

By  
Lisa Ann Walker-Vischer

A doctoral project in partial fulfillment of the  
requirements for the degree of Doctorate of Nursing  
Practice in the California State University, Northern  
Consortium, Doctor of Nursing Practice Program,  
California State University, Fresno

May 2014

APPROVED

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\_\_\_\_\_  
Lisa Ann Walker-Vischer  
Doctoral Project Author

\_\_\_\_\_  
Constance Hill  
Chairperson's name (Chair)

\_\_\_\_\_  
Nursing  
Department name

\_\_\_\_\_  
Suzanne S.Mendez  
Committee member's name

\_\_\_\_\_  
Pediatrics  
Department name

\_\_\_\_\_  
Karen Wayman  
Committee member's name

\_\_\_\_\_  
Family Centered Care  
Department name  
or professional affiliation

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## **Dedication**

This doctoral project is dedicated to my father, William L. Walker, who shared his love of learning and always believed that I could do anything, even when I didn't.

## **Acknowledgments**

First I would like to thank my family, Tom, Kelsey and Mackenzie Vischer for their love and support throughout my doctoral program. You gave me strength, love and patience when I needed it most. I could have never done this without you three.

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The Experience of Latino Parents of Hospitalized Children During Family Centered Rounds

Lisa Walker-Vischer, RN, MS. DNP (c), CNS

California State University, Northern California Consortium

Doctor of Nursing Practice

School of Nursing

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### Abstract

**Problem:** Hospitalization of a child is stressful. The parental role is altered and parents have a primary need to receive timely information. Family centered rounds (FCR) provide a mechanism to exchange information and facilitates shared decision making with the medical team while parents advocate for their child's needs. FCR has been linked to increased satisfaction and improved outcomes. A recent study suggests that Latino parents have a suboptimal experience related to language barriers and a lack of empowerment. The purpose of this study is to describe the experience of Latino parents of hospitalized children during FCR in a public safety net hospital.

**Methods:** Using a convenience sample, written surveys in Spanish were given to 20 parents who were self identified as Spanish speaking and had attended at least two FCR. Basic demographic data was collected. The surveys were translated into English for data analysis.

**Results:** Demographics results: 88% mothers; average age of parent 36 years; average age of child 9.9 years; 41% had previous experience with a hospitalized child; 94% were from Mexico; 6% had not attended high school; 59% had attended some high school; 18% graduated high school and 18% attended some college; 82% spoke no English, 100% spoke Spanish at home; the average number of days in the hospital at the time of survey was 4.8; 70% were hospitalized in the Pediatric Unit, 18% in the Pediatric Intensive Care Unit and 12% in both. The narrative data was analyzed for common themes using an inductive approach to content analysis. Four themes were identified: valued perception, inclusion and care, facilitated communication, and meeting expectations.

**Conclusions:** Parents report a generally positive experience during FCR. They felt their participation and input were valued and that it positively impacted their child's care. FCR

helped them better understand the plan and facilitated communication between parents and the healthcare team when information was conveyed in Spanish. Latino parents want and expect to be involved in decisions affecting their child. Finding ways to increase the number of Spanish speaking staff is key.

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### The Experience of Latino Parents of Hospitalized Children During Family Centered Rounds

A focus on family centered care emerged in the 1980's after the Surgeon General released his report on the care of children with special needs (U.S. Department of Health and Human Services, 1987). In that report, the role of parents as the constant in the child's life was first recognized and the importance of the family unit in decision-making was acknowledged (U.S. Department of Health and Human Services, 1987). As this concept has evolved and operationalized over the last 25 years, the practice of family centered bedside rounds (FCR) has been adopted in many pediatric and pediatric intensive care units (PICU) nationally (Mittal et al., 2010). The American Academy of Pediatrics (2003) recommends attending physicians conduct rounds in the child's room with the parents/family present as a way to exchange information and encourage shared decision-making. More recently FCR has been associated with shorter length of stay, reduced medical errors and higher parent and staff satisfaction (American Academy of Pediatrics, Committee on Hospital Care and Institute for Patient and Family Centered Care [AAP], 2012)

Hospitalization of a child is a very stressful event for most families. Hospitals are an unfamiliar, often unfriendly environment. Parents may perceive the outcome as uncertain, the experience painful for their child and the experience full of intense, often fluctuating, emotions (Aldridge, 2005). Since the environment is so foreign it is hard for parents to anticipate what is coming next. The parental role is altered and parents may experience a loss of control as 'strangers' care for their child in ways that they cannot (Mullen & Pate, 2006). Curley and Myer (2001) identified that parents had a primary need to receive as much information as possible regarding their child's condition and any issues that are present. FCR provides a mechanism to relieve stress for the parents by providing them with information and anticipatory guidance about

what to expect next. It allows them to share decision making with the medical team and advocate for their child's needs in a formal setting.

In 2003, the American Academy of Pediatrics endorsed the concept of family centered rounds but only defined them as "attending physician rounds conducted in the patients' rooms with family present" (p. 693). As the concept of family centered care has expanded into the adult world, the Institute of Medicine (2001) recommended a focus on the patient as the priority for healthcare design. They cite the patient/family as the source of control over health care decisions and acknowledge the importance of shared knowledge and the free flow of information between the clinician and patient (p. 8). In 2010, the Joint Commission endorsed a patient centered approach with a focus on communication needs for the patient and family (Joint Commission, 2010). The National Quality Forum also supports person and family centered care as a way to improve quality, safety and reduce healthcare costs with a projected savings of 9 billion dollars over 10 years ("National Quality Forum," n.d). While all these national organizations endorse a family centered care model, pediatric practitioners have been doing it for over 30 years.

The definition of FCR is often vague and varies from organization to organization. Much of the literature focuses on location (bedside rounds) or participants (family presence) but fails to go further to describe the difference between rounds conducted at the bedside and true family centered rounds. Sisterhen, Blaszak, Woods and Smith (2007) completed a review of the literature in an attempt to define FCR. They describe the key difference between FCR and bedside rounds as the active participation of the patient and family in the discussion, not just conducting rounds at the bedside (Sisterhen, Blaszak, Woods, & Smith, 2007, p. 320). This distinction is key to the goal of increasing communication between the family and the healthcare



team. The question to be answered by this study is what is the experience of Latino parents of hospitalized children during FCR.

### **The Problem**

In 2009, over 3 million children were hospitalized nationally (Child Health USA 2011, 2011). In 2012 there were over 2300 pediatric admissions at Santa Clara Valley Medical Center (SCVMC) (Department of Pediatrics, Santa Clara Valley Medical Center, 2012). Fifty-six percent of patients at SCVMC are self-identified as Latino (Regenstein & Sickler, 2006). Latino's make up the fastest growing minority group in the United States and are expected to be the largest racial/ethnic group in the United States by 2050 representing 36% of the total population (Santa Clara County Public Health, 2012).

For Latino families, there are significant barriers to participation in FCR (Seltz et al., 2011). These include language barriers during family-healthcare team communication, a sense of a lack of empowerment to ask questions and feeling they were bothering the staff with requests (Seltz et al., 2011). Seltz et al. (2011) also identified that families want to decide who from their family can participate in FCR. Some families want extended family and others felt inhibited by the extended family. Finally Seltz et al. (2011) identified that families appreciated when their cultural needs were met and could often see the intent even if their needs were not ultimately met. Seltz et al. (2011) have the only published article that specifically describes the experience of Latino parents during FCR.

At SCVMC there are no written materials that describe FCR in detail for our families. We do not have an in-person interpreter available during the rounding process and rely on residents or nursing staff with varying levels of Spanish proficiency for daily updates. Thirty seven percent of Latino adults in Santa Clara County do not have a high school diploma resulting

in issues with reading and understanding the complex nature of diagnosis and discharge instructions (Santa Clara County Public Health, 2012). Rounds are often conducted in complex, detailed medical language and then summarized very briefly for the family. This may foster feelings of exclusion for the families. The nursing staff encourages participation in FCR but does not actively attempt to empower families to be active participants. In order to meet the needs of over half of our population, more attention must be paid to the experience of Latino parents during FCR.

### **Communication Issues**

The key component to patient-provider communication is the ability to accurately exchange information (Chen & Jacobs, 2007). It affects the ability to communicate not only during the visit, but also affects the ability to make appointments or access resources in the future (Chen & Jacobs, 2007). Subramony, Schwartz and Hametz (2012) reported that FCR generally increased knowledge about the discharge plan and goals but less so for Spanish speaking or Latino parents. Lion et al. (2013) identified two common practices used during FCR with parents with limited English proficiency (LEP): conducting the medical discussion without the parents and second, relying on the medical interpreter to decide what information was important to convey and what was not. This leads to decreased comprehension that may be directly related to the filtering aspect of the communication. In 2011, Watts, Cowden, Cupertino, Dowd and Kennedy completed a study that explored the perception and attitudes regarding pre-hospital care (911) in Spanish speaking parents. Parents reported concerns about not knowing what constitutes a medical emergency, and concerns and frustration about their inability to communicate with non Spanish-speaking personnel. They also expressed fear of their immigration status being exposed and a perceived cost to the service. As a result, most

children were transported to the hospital by their parents as opposed to 911 services, potentially resulting in significant delays in care.

Being able to communicate symptoms, feelings, concerns and emotions is key to a therapeutic interpersonal relationship (Ayonrinde, 2003). This information is essential for the provider to diagnose illness, provide resources and promote shared decision making with the parents. Studies indicate that patients with limited English proficiency (LEP) receive lower quality care, especially related to preventative services, but ironically seem to receive excessive diagnostic testing in the emergency department setting, more hospitalizations and longer length of stays than similar English speaking patients.

Parents with LEP miss out on the free exchange of ideas and feelings that English speaking patients experience. Phone interpretation is an awkward process that interferes with the flow of ideas but is the mainstay of formal interpretation services in most hospitals. SCVMC has telephone interpreter services available 24 hours a day, 7 days a week and provides translation for over 120 languages and dialects ("Language services," 2012). Language services cites a wait time of no more than 5 minutes and then the call is directed to AT&T language services, an outside provider. In this author's experience, the outside providers have less experience with medical interpretation than the in-house interpreters at SCVMC. California state law, Senate Bill 853 requires translation services in health care settings (S. Res. 853, 2003). The Joint Commission (2011) released a video in late 2009 urging health care organizations to focus on removing language access barriers. All these regulations are an attempt to improve communication between health care providers and patients with LEP.

Interpretation services come with their own set of challenges. Abbe, Simon, Angiolillo, Ruccione and Kodish (2006) reported attitudes and perspectives of pediatric oncologists, trained

interpreters and Spanish speaking parents in a pediatric oncology practice. Their results indicate that interpreters are a very important resource but not entirely sufficient to prevent a language barrier (Abbe et al., 2006). Oncologists expressed concern about accuracy and completeness of the interpretation in light of the complexity of the information that needed to be conveyed. Interpreters were concerned about the complexity of information, the overwhelming amount of information and lack of clinical sensitivity expressed to the parents. Parents were most concerned with missing important information and comprehension issues that were above the interpreter's level. All three groups shared concerns about the complexity of the information and difficulty understanding the information by the parents and some of the interpreters. This study highlights the need for much improvement in our current model of interpretation, even with well-trained experienced interpreters.

Interpretation issues can lead to significant miscommunications in the health care setting and delays in care with tragic consequences (Flores, 2006). In a small pilot study done by Pham, Thornton, Engleberg, Jackson and Curtis (2008), the researchers studied types, prevalence and potential effects of alterations in interpretation. The study used trained interpreters during end of life conferences in an adult intensive care unit. Their results were disturbing: there is a 55% chance that an alteration would occur in each exchange and for those alterations categorized as significant, there was a 93% chance it was likely to have a negative effect on communication. While they acknowledge that further study is warranted it is clear that current models of interpretation may be inadequate for complex, highly emotional communications.

Cross-cultural communication presents a distinct set of challenges. We are all products of life experience, cultural norms, assumptions, and expectations and come into interactions with the bias of our cultural perspective (Bigby, 2007). Since it is impossible to be aware of the

nuances of all cultures, it is important that health care providers take the time to find out what the patient believes about their illness, what they know about how their body works and to avoid stereotyping of individuals in a cultural group (Bigby, 2007). Health care providers must avoid jargon and help break down complex information into layperson's terms for all of our patients. Health care professionals must verify understanding with our patients and create that ideal trusting therapeutic relationship in order to bridge the cross-cultural divide (Bigby, 2007). This results in more time needed to convey information and verify understanding than current healthcare cultures allow. Health care professionals must be aware of their own biases and beliefs and honestly consider how they affect our interactions with patients and families.

Communication is so much more than the words that are used. Less than 10% of the emotional communication during a medical interaction is verbal (Ayonrinde, 2003). Tone of voice contributes about 22% and eye contact and body posture account for approximately 55% of the communication. Culture determines how one experiences these interactions.

These issues related to limited English proficiency (LEP) and cultural differences set the stage for a less than optimal experience for parents during FCR. Seltz et al. (2011) is the only published study that looks at this issue and used focus groups to explore the experience for Latino parents during FCR. The results of this study indicate that LEP families did not consistently receive family centered care during FCR. They cite that language barriers and lack of family empowerment negatively affect optimal communication.

### **Theoretical Framework**

Davidson's theory of facilitated sensemaking (2010) provides a framework to approach families both from the nursing intervention side as well as a way to describe the process that families go through when a loved one is in an intensive care unit. Davidson describes two

sensemaking goals: making sense of what is happening now and what the family should do now (Davidson, 2010). This theory provides a set of nursing interventions to facilitate helping families make sense of what has happened to the patient and to identify their new role as a family member of an ill person. Sensemaking is an ongoing process and must be repeated as the patient's condition changes.

Judy Davidson is a doctoral prepared Clinical Nurse Specialist and director of advanced practice nursing and research at a prominent California Hospital. Davidson's theory originates out of the common issue of dealing with families in these high stress situations. Much may be misinterpreted by the family and in turn cause stress, anxiety and grief. Nursing is often unsure of what to do to help families through these tough times. Davidson (2010) proposes that by making sense of what is happening and understanding their new role with their loved one, that families will experience less grief, anxiety and distress.

Facilitated sensemaking is a middle-range theory and as such is intended to guide practice directly at the bedside (Davidson, 2010). This theory was developed from Roy's adaptation model (Roy & Andrews, 1999) and Weick's theory of organizational sensemaking (Davidson, 2010). Roy's model describes the need to adapt to the new situation but does not tell nursing what to do to help this process. This forms the foundation that facilitated sensemaking is based on (Davidson, 2010). Weick's theory was originally developed in relation to how leaders shape organizational image (Davidson, 2010). He related that we all receive cues from our environment, but each of us may interpret the cues differently and come away from an interaction with a very different perspective.

Sensemaking is also defined as a "process of social construction that occurs when discrepant cues interrupt individuals' ongoing activity and involves retrospective development of

plausible meanings that rationalize what people are doing” (Maitlis & Sonenshein, 2010, p. 552). This definition helps explain the common experience nurses have after the physician has talked with a family and the family has heard or interpreted the information completely differently than the physician intended. Davidson proposes that through facilitated sensemaking, nurses help families sort these cues into meaningful information and help them adapt to the new situation. Her work was heavily influenced by her research on rates of long-term depression, anxiety and posttraumatic stress disorder (PTSD) in families of ICU patients. This finding led to the development of facilitated sensemaking as a way to reduce the trauma experienced by families in the harsh ICU environment.

The assumptions of this theory include: fear and helplessness are common experiences of ICU families, nursing interventions can reduce this issue, unmanaged fear and anxiety increase the risk of PTSD, and adaptation can be either positive or negative. Hospitalization of a child is a very stressful event and often families don’t even know what they need to know or do to move through the process. They are often immobilized by the stress of the hospitalization. Board and Ryan-Wenger (2002) found that mothers in particular may have significant stress related symptoms up to six months after the child’s illness. Nursing needs to provide anticipatory guidance and clarification for families in this very stressful foreign environment. Some of the families that become identified as difficult or problematic are really results of unmanaged fear and anxiety. They lash out at staff in inappropriate ways trying to find some control in the out of control situation of a critically ill child in a pediatric ICU. When information to clarify fears and concerns is provided and emotional support given then many of these parents will calm down and be more constructive in their approach with the health care team. The need for parents to know what to do in this new environment is very underrated. Giving clear direction on how to

help and be involved in their child's care is very important. Davidson proposes assigning tasks to help with the role redefinition. They must be socialized to the new environment and be given information on what to expect. For example, PICU's are a very noisy environment with alarms on every piece of equipment. With direction, parents quickly learn how to interpret which alarms are important and which are irrelevant.

One of the most common admissions to the PICU and Pediatric unit are children with unplanned traumatic injuries. Essentially this is every parent's nightmare. They are thrust into a high tech, high intensity environment. Not only is the primary language English, it is a highly sophisticated medical English. Even English speaking families may struggle with understanding in light of the medical jargon and terminology. It is fast paced and they are expected to help make decisions about the care of their child during FCR. They often have very little formal education and are overwhelmed by the level of information provided to them. It is important to remember that families may not have questions because they are so overwhelmed at this point in time.

Facilitated sensemaking will support the bedside nurse in interpreting the cues from the family and resorting the cues to help them make sense of what is happening to their child. The nurse will get to know the family and build trust that will lead to increased communication. This will help the nurse be able to clarify misunderstanding and misinterpretation of the current condition of their child after FCR. The family will then be able to form questions as a result of this increased communication and support. Through this relationship and process the nurse will be able to help the parents find their new role as a parent of an acutely ill child.

Davidson (2010) contends that this theory was developed both inductively and deductively and completed an extensive literature search on family experience in the ICU to



determine the concepts for this theory. She states that “planned nursing interventions to decrease family member’s fear, horror and helplessness while helping the member make sense of what has happened and what are their new roles” (p. 34). Concepts derived from Roy’s model include family disruption, compensation and adaption. Weick’s model contributes the concepts of making sense of what has happened and making sense of the new role. The theory proposes that with nursing intervention one can help families make sense of what is happening to their loved one and make sense of their new role as a family member of a critically ill person. These interventions include empathetic listening; potential care conferences and referrals, reflective inquiry, end of visit clarifications, review of unmet needs, questions for physicians and bedside activities. These interventions promote compensation to the new situation. They minimize fear and horror while decreasing feelings of helplessness. This in turn promotes adaptation to this new reality.

### **Literature Review**

For the purpose of this paper, 12 articles on FCR will be reviewed. While there is literature on FCR in neonatal and adult units, only studies conducted in pediatric inpatient units, including pediatric intensive care units, were reviewed for this paper. There is one systematic review, two randomized controlled trials, three prospective observational studies, one quality improvement project, two qualitative descriptive studies, one mixed method study, one observational study and one quasi-experimental study done in a pediatric population.

The oldest article to be reviewed is from 1988 and uses an inpatient pediatric oncology unit as its site (Lewis et al., 1988). This study represents the first of only two randomized controlled trials on FCR. Researchers alternated bedside rounds with standard rounds as defined as “rounds conducted out of earshot” (Lewis et al., 1988, p. 378) in 2-week blocks for 4 months.

This resulted in 3 groups: those who only experienced bedside rounds, those who only experienced standard rounds and a mixed group that experienced both. Questionnaires were given to parents, patients and physicians. Demographics of the sample included Hispanics (12%) and White (80%). This study found that bedside rounds have a positive impact on parents' attitude towards physicians and may contribute to certain aspects of resident education (Lewis et al., 1988).

The second randomized controlled trial was conducted in a pediatric intensive care unit in Canada (Landry, Lafrenaye, Roy, & Cyr, 2007). Randomization was done on the first case presentation to either bedside or conference room and then switched to the other the next day. Questionnaires were completed by the resident and parents after each round. Twenty-seven parents of 22 patients completed both questionnaires and 22 residents completed questionnaires. Parent satisfaction was significantly higher during bedside rounds. There was a significant preference for bedside presentation and bedside teaching. There was no significant preference for rounding type by residents but they were more comfortable asking questions and being asked questions during the conference room rounds. This study supports the feasibility of FCR in inpatient units.

Rosen, Stenger, Bochkoris, Hannon, & Kwoh (2009) conducted a quasi-experimental study to gain a better understanding of the patient and family experience with FCR, value for the staff of FCR and difference in time commitment for FCR versus conventional rounds. The study was conducted over two weeks in an adolescent unit and patients admitted during the first week were assigned to conventional rounds conducted in the conference room. Patients admitted during week two were assigned to the FCR group with rounds conducted at the bedside. Time on rounds was calculated for both groups. Parents and patients were surveyed at the end of each

morning as well as the staff involved with each rounding type. Results from the 36 patient/parent surveys suggest there was no significant difference in parental/patient satisfaction between the CR and FCR group. There was a significant impact on staff satisfaction related to improved communication between the family and staff, greater understanding of the plan of care, a greater feeling of working as a team and a greater ability to deal with families' concerns during FCR during the FCR weeks. Greater than 80% of the staff surveys were completed by non-physicians. Time to complete FCR was slightly longer per patient but was not significantly different. While there was the unexpected finding of no difference in parent/patient satisfaction, there was a significant difference in staff satisfaction (Rosen, Stenger, Bochkoris, Hannon, & Kwoh, 2009). Ethnicity was collected as part of the demographic data but results were not reported.

Seltz, et al. (2011) attempted to characterize the experience of Latino families during FCR to identify areas of improvement. Using focus groups with a bilingual facilitator that was not part of the medical team, they asked seven standard questions for each group. Twenty-eight family members of 21 hospitalized children participated. The results of these focus groups identified four unmet needs of Latino families: need for fluent bilingual interpreters, preferably in person, lack of empowerment to ask for interpreter or to ask questions about their child's condition, issues with family members present or not present during rounds and a need to address cultural needs.

Four studies employed a prospective observational design (Aronson, Yau, Helfauer, & Morrison, 2009, Cameron, Schleien, & Morris, 2009, Phipps et al., 2007, Rappaport, Ketterer, Nilforoshan, & Sharif, 2011). All four studies found increased parental satisfaction with FCR but three of the four reported some perceived alteration in resident education. Only one of these

four studies reported the ethnicity of the participants and it was predominately White (Aronson et al., 2009).

Two other studies involved semi-structured interviews or surveys to describe the parental experience of FCR (Latta, Dick, Parry, & Tamura, 2008, McPherson, Jefferson, Kissoon, Kwong, & Rasmussen, 2011). Both concluded that parental participation in rounds was beneficial for parents. Finally, Kleiber, Davenport, and Freyenberger (2006) reported on their change to inclusion of parents during bedside rounds in a 12 bed PICU in Iowa as part of a quality improvement project. They used surveys for parents, nurses and physicians as well as monitored the length of time it took to complete rounds. They reported a perceived benefit by physicians, nurses and parents.

There is a single systematic review of the literature on family presence during rounds (Cypress, 2012). It includes studies on adults and neonates as well as pediatrics. Cypress (2012) asks the question "In critical and noncritical pediatric and adult patients does the family presence on rounds compared with non-inclusion of family members lead to positive outcome and increased satisfaction" (p. 55). One hundred thirteen articles were reviewed and 19 were included in the systematic review. Search strategy is well described and the individual articles are presented in a clear table within the article. The Scottish Intercollegiate Guidelines Network Grades of Recommendations and Level of Evidence were used to rate the level of evidence for each study. Cypress (2012) acknowledges that RCT may not be practical for this research question and emphasizes the need for a more qualitative approach in evidence based practice literature. She advocates for qualitative research to be higher in the hierarchy of evidence based practice. FCR was generally viewed as positive by family members, patients and health care providers and lead to increased satisfaction when compared to non-inclusion of family members.

The conclusion of this systematic review was that FCR has the potential to create a patient centered environment, enhance both medical and nursing education and improve patient outcomes (Cypress, p.63, 2012).

### **Critique of the Literature**

Randomized controlled trials have long been considered the gold standard of evidence-based practice (Powers, 2011). Many research questions do not lend themselves to an RCT design and are better served through qualitative research. Since the implementation and evaluation of FCR involves the experience of the individuals involved, the research is mainly qualitative. Powers (2011) describes a tool for rapid critical appraisal of qualitative evidence. Using this tool, the studies reviewed provide strong evidence that FCR are beneficial for parents of hospitalized children. Participants were chosen from a variety of pediatric inpatient units including critical care. Results were accurately and completely obtained and the results were believable to those of us with a pediatric practice. Initially there was great concern by the medical team about confidentiality breaches with conducting rounds at the bedside, but the vast majority of parents did not share this concern. Residents and other trainees get a firsthand experience at working with families and role modeling of these skills by more experienced practitioners. As a nurse for 27 years, the results of all 12 studies are plausible and believable and you are drawn into the experience of the participants as they have an opportunity to advocate for their children. The purposes of all 12 studies were clearly stated and the results supported the original research question. Language and concepts were consistent with the study approach and data collection and analysis was appropriate for the research as stated. Until recently there was not a large body of literature on FCR and there were still concerns about the feasibility of conducting rounds at the bedside with parents as active participants. There has been significant

concern by physician colleagues about increased time to conduct rounds and an over concern about confidentiality issues. These 12 studies support the need for FCR in all pediatric units and the inclusion of parents in a shared decision making model. Samples in all 12 studies had some element of convenience, even in the RCT where all patients on certain days were randomized to one group or another. The sample of hospitalized children in a variety of settings is well done within this body of literature and enhances generalizability, but sample sizes of the individual studies were often small. Most studies measured satisfaction only and just briefly described the actual experience of FCR for families with the exception of the Seltz et al. (2011) article. Methods to collect data are well described in all 12 studies as were researcher roles and responsibilities. Data collection and analysis is well described and well presented in all the reviewed articles and results are reported in a clear logical manner, often using tables or charts for clarity. Findings were presented in a clear manner in all studies and quotes enhanced the readers understanding of the experience particularly in the Seltz et al. (2011) article. Overall the results are well represented and the articles are well written. Finally, Powers (2011) asks will the results help me in caring for my patients? This author firmly believes that FCR enhances the teamwork between parents, patients and the health care team. This in turn has the potential to improve outcomes for the patients involved.

All 12 studies used some form of questionnaire or survey to elicit responses. However, only three studies provided information on validity or reliability of the tool used (Cameron et al., 2009, Rappaport et al., 2011, Seltz et al., 2011). Very few studies described the ethnicity of the parents or children and those that did were predominately white with the exception of Seltz et al. (2011).

FCR is still a vastly understudied topic. The lack of well-defined reliable outcomes for FCR makes research difficult and as Cypress (2012) notes, studies designed as RCT may not capture experience for families accurately. Additionally, the majority of studies focus on the experience of the parents and the physician with nursing being mentioned in only a few and often reported as a minor finding. Finally, Cypress (2012) reminds us that qualitative research gives a voice to our patients and that we must be careful not to disregard it especially for issues that do not lend themselves to RCT designs.

## **Methods**

### **Project Design**

This is a qualitative, descriptive study to describe the experience of Latino parents of hospitalized children during family centered rounds. A survey format was used to elicit a description of the experience. The results will be used to design interventions to improve the experience during FCR.

### **Setting**

This study was conducted in the pediatric unit and pediatric intensive care unit of a 500-bed public safety net hospital in an urban setting in the fall of 2013.

### **Population and Sample**

Participants were self identified Latino parents of hospitalized children in the pediatric unit and pediatric intensive care unit at SCVMC who identified their primary language as Spanish. Inclusion criteria was also the ability to read and write in Spanish and attending at least two FCR to ensure that parents had some experience with the process.

This study used a convenience sample of pediatric patients admitted to SCVMC. The investigator reviewed the census daily on Tuesday through Friday for patients that met the

inclusion criteria. Parents were approached by the investigator using a Spanish-speaking staff member and offered the opportunity to participate by completing the 14-question questionnaire. 56% of patients admitted to SCVMC are self identified as Latino, but a smaller group identifies their primary language as Spanish (Regenstein & Sickler, 2006).

### **Intervention/Instrumentation**

A 14-question survey was developed using the work of Seltz et al. (2011). Basic demographic data without patient identifiers was also collected. In the original study, several questions asked about doctors and nurses in the same question. For this study, those combined questions were split into two questions. Also several questions only addressed the role of the physician so a corresponding question was asked that addressed the role of the nurse. Finally one question was added at the end of the questionnaire that asked if there was anything else they would like to tell us about their experience. See Appendix A for the survey. The survey was then translated in to Spanish using the Language Services department at SCVMC.

### **Data Collection**

Parents were verbally approached by the investigator and a Spanish-speaking staff member and offered the opportunity to participate. The investigator explained that the goal of the study was to understand what the experience of FCR was for our Spanish speaking families. We hoped to use this information to improve how we conducted rounds. Subjects were encouraged to be honest, both good and bad, and were assured that the results were anonymous and would not affect the care of their child. They were also provided a written invitation to participate with the same details in Spanish. See invitation to participate in Appendix B. The written survey, a pen and a large manila envelope were provided with instructions to return to the investigator or unit clerk within the next 24 hours. All 20 parents agreed to participate and 17



surveys were returned for a return rate of 85%. The unit clerk and the staff nurse for that shift were asked to check back with the family and encourage the completion of the survey. They were reminded to page the investigator if there were any questions. Information was provided to the nursing staff regarding the study and their role in returning surveys to an identified folder in the nurse's station of both units. Data was collected over the 6-week period of October 1, 2013 to November 8, 2013. Surveys were returned in a sealed individual envelope and placed in a single file folder for analysis as a group to minimize any opportunity for inadvertent identification of the subject. Surveys were numbered after returned to the investigator to aid in data analysis.

### **Data Analysis Plan**

A bilingual research assistant translated the surveys from Spanish to English. The English version was analyzed for common themes using content analysis techniques. Content analysis methodologies were used with an inductive approach to identify general themes from the surveys (Elo & Kyngas, 2007). The goal of content analysis is to develop a broad description of the studied phenomena with the outcome of the analysis being concepts or categories that describe the phenomena (Elo & Kyngas, 2007). Conventional content analysis as described by Hsieh and Shannon (2005) was employed. Using the research question, what is the experience of Latino parents of hospitalized children during FCR, the surveys were sorted by question and read by the researcher until content saturation is reached. Each subject response was read and the exact words or phrases were highlighted that captured the essence of the response. Then these were "named" to describe the phenomena. Finally, the named data was grouped into themes. The co-investigator completed the same process and results were compared.

Additionally, the results were read in Spanish by a parent volunteer to evaluate if subtle content was lost in the translation process.

### **Ethical Considerations**

The study was submitted to the institutional review board (IRB) at both Santa Clara Valley Medical Center and Fresno State University and determined to be exempt from further IRB review due to the low risk nature of the study. There was no protected health information collected so anonymity was assured. Subjects were assured that their responses were anonymous and would not affect the care of their child in the hope that it would allow parents to be more open and honest in their responses. The investigator did not know the majority of the subjects but had interacted in a professional capacity with several of the subjects. This may have encouraged participation but ideally should not have affected the parent's responses.

### **Trustworthiness**

While it is impossible to not have some bias within a research question, the goal is to not have it affect the study. This investigator assumed that Latino parents would describe a less ideal experience and that this data would direct the development of interventions to improve that experience. When describing the study to potential subjects, the words used were carefully chosen to not represent this bias and the investigator asked parents to describe both the good and the bad of the experience during FCR. The introduction letter was also carefully worded to not represent the bias and only ask about the experience.

### **Summary**

Twenty families agreed to participate and 17 surveys were returned completed. These were analyzed using content analysis to identify the predominate themes used to describe the experience.

### Results

Basic demographic data was collected as part of the survey. The sample was made up of 88% mothers with an average age of 36 years (range 30-44). The average age of the child admitted was 9.8 Years (range 3 months-18 years). 41% reported previous experience with a child in the hospital. 94% were originally from Mexico. One subject or 6% reported only attending grades 1-5. 59% reported attending some high school. 18% reported graduating high school and 18% reported attending some college. 82% reported speaking no English, while 12% hand wrote in the option of “un poco” or a little. Only one parent reported speaking English. All subjects reported that they spoke Spanish at home. They had been admitted an average of 4.8 days at the time of the survey (range 2-11). 70% of the patients were admitted solely to the pediatric unit, 18% solely to the pediatric intensive care unit and 12% were cared for in both units.

Table 1

#### *Demographics*

Characteristic	Value
Relation to patient	
Mother	88%
Father	12%
Median parent age, y (range)	36 (30-44)
Median patient age, y (range)	9 (3m-18)
Previous experience with child in hospital	41%
Country of origin	
Mexico	94%

Nicaragua	6%
Education level	
Less than high school	6%
Some high school	59%
Graduated high school	18%
Some college	18%
Speaks English	
Yes	6%
Un poco	12%
Spanish spoken at home	100%
Median number of hospitalized days (range) at time of survey	4.8 (2-11)
Hospitalized Unit	
Pedi	70%
PICU	18%
Both	12%

Content analysis identified 4 themes: valued perceptions, inclusion and care, facilitated communication and meeting expectations (Table 2). Speaking Spanish was also identified as an important component of FCR.

Table 2

*Taxonomy of Named Codes into Themes*

**Valued Perceptions**

Collaborative

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Felt Safe

Trust building

Recovery is valued

Decision maker

Participatory

Shared decision making

Felt heard

Solicited information

**Inclusion and Care**

Kind

Calm

Involved in care

Collaboration of team

Attentive

Valued

Reassured

Thankful

**Facilitated Communication**

Explained

Gained understanding

Provided information

Answered questions

Spoke Spanish

Interpreters

Did not speak Spanish

Don't understand

Accessible

Provided details

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**Meeting Expectations**

Met needs  
Anticipated needs  
Provided understanding  
Updated  
Clear  
Tried to speak Spanish  
Not reliable  
Don't understand the plan  
Didn't provide information  
More kindness and consideration  
More anticipation of needs

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**Valued perceptions.**

Parents describe feeling that their participation, perceptions and input are valued. They describe feeling acknowledged and that there is a shared goal between the parents and the medical team of recovery for their child. One mother said, "I feel the child's recovery is important to both the nurses and parents". When asked about how they felt participating in decisions regarding their child's health, another mother said, "It was very important because we the parents know our child's behavior at lot better. With our help the doctors can do a better job". Another mother said, " It is a very good idea (participating in decisions), that way I feel like acknowledged which makes me more comfortable". There is a clear sense that the parents feel they are an important part of the team. When asked about how she felt she was included in rounds, a mother said, "safe and that my opinion matters". Parents felt heard by the team and felt there was trust built by being included in the decision making process.

**Inclusion and care.**

Parents felt included in the rounding process and felt that their child's care was better because they participated. A mother said, "I like it when they involve the parents in the patient's treatment plan". Many subjects commented on the kindness and attentiveness of both the medical and nursing staff and felt this made the hospitalization easier for both the child and the parents. Multiple subjects noted the collaboration between the team and the family. A father said, "I don't speak English but I was always included in the conversations and with any decision that were made". Parents felt it was important for nursing to be involved in FCR for two distinct reasons: for the nurse to better understand the plan and provide better care and second to interpret the plan for the family throughout the stay. The words comfortable and safe were frequently used to describe the experience and there is a sense that families feel included and cared for both by the medical team and nursing. Several subjects reported feeling comfortable asking questions or for further explanation if needed. The words kind, trust and comfortable were frequently used in responses about the experience.

**Facilitated communication.**

The results of this study support that FCR increased communication between families and medical staff. Numerous subjects report that FCR helped them better understand what would happen in the hospital. They acknowledged both the role of the medical staff and nursing in helping them understand and expressed feeling comfortable asking questions or for clarification on whatever they didn't understand. A mother said, "they (nurses) tried to help so I could understand". When asked how well did they understood the plan for the day, one mother said, "I felt better after they explained it to me" indicating that there was some conversations that focused on clarification of the plan. Another mother said, "I understand it very well and I will

follow it at home as well”. A father said, “They (doctors) explained step by step. Also they answered all of our questions”. A mother said, “They (doctors) explained in detail. They answered all my questions even if I had to ask more than once”. This reflects the complex nature of the material that needed to be communicated. When asked what nursing did to help you understand the plan a mother reported, “ They answered all my questions about any medications and about the plan”. Another mother describes said, “ They (nurses) provided me with good information and examples about the problems so I can better understand”.

They reported that explanation in Spanish was essential and if they did not understand the plan or what was said during FCR, then a staff member who spoke Spanish would help them understand after rounds. Interpreters were mentioned frequently as being important, but one mother stated that the child was used to translate. This warrants follow up and staff education about not using family members to interpret for medical conversations.

### **Meeting expectations.**

Most subjects reported that their needs were met and cited that the staff was approachable and attentive. One mother who had previous experience with a hospitalized child reported, “This time was better.” Another mother said, “I believe it (rounds) went very well because the nurses were always making sure our needs were met”. There were some negative comments regarding physicians agreeing to come back later and explain things and then not coming back that reinforces the importance of following through with commitments to patients. There was also a request for physicians to visit the patient more than once a day. It is unclear if this request is for more medical attention or if there is a desire to build more relationship with the medical staff. It was also reported that it would be nice if nursing asked parents if they needed anything instead of them having to ask. This highlights the need to develop a plan to better anticipate needs.



**Discussion**

We found that this group of parents had a generally positive experience with FCR and that information was communicated in Spanish more often than the investigator expected. They report that staff was kind and helpful and that they generally felt comfortable and safe. Unlike the parents described in the article by Seltz et al. (2011), this group felt empowered to participate, to ask questions and get the information they needed. They felt like a valued member of the team and felt included in the process, all for the benefit of their child. When parents feel their perspective is valued there is a shared power in the relationship and opportunities for empowerment for the parents. This empowerment can lead to more active participation in their child's health care and result in better health outcomes (Amendola, 2011).

The vast majority of parents commented on all that both the medical team and nursing did try to help them understand the plan and the next steps for their child. Two families reported not understanding the plan and having difficulty with communication. It is unclear if they had a different experience than the other subjects or if there were issues with health literacy or language barriers that complicated the communication.

Finally, while the majority of parents felt their needs were met, there was an issue with follow through from the medical team. Parents expressed the desire to have predictable follow up to inpatient issues and wanted more time with the physicians. They also expressed that while nursing was very responsive to their needs when they requested something, they would like to be asked if they need anything instead of having to initiate the request each time. This highlights the need for both medicine and nursing to anticipate the needs of the families.

It is clear that to meet the needs of Latino parents of hospitalized children information must be delivered in Spanish. Our staff has a wide range of proficiency in Spanish and this may

lead to miscommunication. Ideally, there would be certified interpreters available during the rounding process but there are not resources available to provide that service. Another solution is to cultivate more Spanish speaking staff, both physicians and nursing.

### **Limitations**

There were several limitations to this study. The biggest limitation is the small sample size. These results may not represent the broader Latino group of parents hospitalized in this particular hospital, let alone a broader Latino community. The convenience sample may represent a limitation since not all patients who met inclusion criteria were selected. Two surveys were not returned and it is impossible to tell if this represents parents who had a less optimal experience in FCR or did these families represent a group that was too embarrassed to say they couldn't read or write in Spanish. One survey was returned blank and the mother reported that she thought she should only fill it out if she was unhappy. The invitation to participate was done with a Spanish-speaking staff member who was not interpreter certified and exemplifies the subtleties of speaking another language.

The survey format also represents a limitation. There was not an opportunity to clarify or expand on answers so information may not have been as complete as in an interview or focus group format. The survey questions may not have been relevant but the addition of the final question was an attempt to give parents a place to describe anything that was important to them that may have been missed. Parents may have been more positive in describing their experience than they really felt due to worries that it would affect the care their child received.

### **Implication for Nursing Practice**

Both the medical staff and nursing staff play a key role in how families participate in FRC and how information is provided. For the last 12 years nurses have been voted the most

trusted profession in the annual Gallup poll (American Nurses Association, 2013). This trust and the resulting therapeutic relationship allow parents to be comfortable asking questions and obtaining clarification from nursing on the medical plan. The caring role of nursing allows parents to feel safe and comfortable in the vulnerable position of needing clarification or more information.

Nurses clearly have a role in helping parents understand and process information in the highly technical environment of the hospital setting. Parents in this study repeatedly mentioned that the nurse helped them understand or provided them information. This navigation function is enhanced by nursing's proximity to the patient and the development of a trusting therapeutic relationship. Malone (2003) argues that there is a loss of proximity in the current health care environment that decreases how we "know" the patient. This author would argue that interventions like FCR support the proximity of nurses and foster a deeper relationship. They allow nursing to speak on behalf of the patient and family and role model the shared decision making model we strive for. Nursing also has the opportunity to help families understand the FCR process better. Developing written materials that detail the process and the role expectations for parents may be helpful.

Future studies would include a better understanding of staff engagement with Latino families. In the Latino culture there are two cultural scripts that may affect FCR. The cultural script of *respeto*, which is the high regard that is granted to persons solely because of their authority or social positions, may affect a parent's ability to question a physician or the medical plan (Haro, 2011). The cultural script of *simpatía* puts a high value on pleasant relationships and the avoidance of conflict (Haro, 2011). This may also adversely affect a parents' ability to disagree with the medical team. It is important for staff to understand and work within these

cultural scripts and develop ways to support parents in the role of an advocate and decision maker in the hospital setting.

Exploring programs that support the empowered parental role such a ParentWise® may further strengthen the role of parents. ParentWise® utilizes parent volunteers to help empower parents to partner with the healthcare team and advocate for their child. Specially trained parents who have experience in the hospital setting are connected with current parents to provide support throughout the hospital experience. Adapting the program to include Spanish-speaking parents may provide important support for families.

### **Conclusion**

FCR offer a formal process to exchange information between patients, parents and the health care team and supports a shared decision making model. This process can foster a sense of collaboration and trust between parents and the health care team as well as improve parent satisfaction. This study supports that parents want and expect to be involved in the care and decisions affecting their child. They view their role as unique and important to the welfare of their child. Parents appreciate the staffs' efforts in providing information and understanding throughout the stay. Providing information in Spanish is an essential component of satisfaction with FCR. Finally there are opportunities for an improved experience for parents by providing more predictable encounters with the medical staff and anticipating parents' needs before they need to ask.

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**Appendix A**

FCR Questionnaire modified from Seltz et al., (2011)

**Demographic data:**

Relation to patient and age of parent

Age of hospitalized child

Previous experience with child in hospital

Parent's country of origin

Education level

Some High School

Graduated High School

Attended College

Do you speak English?

Language spoken at home

1. Please tell us about your experience with rounds today.
2. How do you feel about your doctors discussing your child's illness in your child's hospital room?
3. How do you feel about your nurses discussing your child's illness in your child's hospital room?
4. Family opinions or preferences may be important in decisions regarding your children's care. How do you feel about participating in the decisions regarding your child's health care?
5. How well did you feel you were included in that discussion during rounds?
6. How well do you understand the plan for the day after morning rounds?
7. What did your doctors do to help you understand the plan?
8. What did you nurses do to help you understand the plan?
9. How do you feel about having the nurse present with your doctors when they discuss your child's care?
10. Please tell us about any language problems that occurred between you and your child's doctors. Tell us about any cultural problems.
11. Please tell us about any language problems that occurred between you and your child's nurses. Tell us about any cultural problems.
12. What do you wish your doctors would do that they have not done?
13. What do you wish your nurses would do that they have not done?

14. Is there anything else you want to tell us about your experience during family centered rounds?

## Appendix B

You are invited to participate in this research study entitled: ***The Experience of Latino Parents of Hospitalized Children During Family Centered Rounds***. The following information is provided to help you make an informed decision about whether or not to participate.

The purpose of this survey is to describe the experience of Latino parents during family centered rounds. We are asking you to participate because you have identified yourself as Latino or Hispanic, reported that Spanish was your primary language and have a child admitted to the Pediatric Unit or Pediatric Intensive Care Unit for at least 2 days. This survey asks 14 questions about your experience during Family Centered Rounds. It should not take you more than 30 minutes to complete it and is completely anonymous. We encourage you to be as honest as possible regarding this experience so we can understand the parent perspective during family centered rounds.

You will be given a copy of this informational sheet to keep. By returning completed surveys, you will indicate consent to participate in this study. Your name will not be collected in order to protect your privacy. Please know that you have the right to refuse to participate in the study or you can discontinue participation in the study at any time without consequence.

The Research and Human Subjects Review Committee of Santa Clara Valley Medical Center has reviewed this study and will review any concerns or complaints you may have regarding your participation in the study or questions you may have about your rights as a research subject. This is a Committee that is concerned with protecting people who volunteer to participate in research studies. The Committee may be reached by calling the office from 9:00 a.m. to 5:00 p.m., Monday through Friday at 408/885-3115 or by writing to the Research Committee, Santa Clara Valley Medical Center, Institutional Review Board Office, 751 South Bascom Avenue, San Jose, California 95128.

This study is being conducted by a Lisa Walker Vischer, RN, CNS as part of her Doctorate of Nursing Practice program. Please contact ***Lisa Walker-Vischer*** with any questions regarding this study at **408-793-2968**.

The Experience of Latino Parents of Hospitalized Children During Family Centered Rounds

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